

Privacy Issues for Community Social Services

.... and more

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ComVoices

A Wellington-based network of national community and voluntary sector organisations

Social Service Providers Aotearoa - SSPA

Represents some 200 NGOs working with children, young people, families and communities

The initial issue . . .

**Individual Client Level Data – ICLD
Must be provided to OT/MSD**

Or in other words . . .

No Data, No Funding

NGOs to hand over people's personal information in return for government funding. A contract requirement.

What information will you will share with MSD?

The following information will be shared:

Client demographic information	Name, date of birth, address, gender, ethnicity, iwi and country of birth
Dependents	Number of dependents Date of birth of youngest dependant
Service detail	Programme/service name, start date and end date, source of referral

MSD is not interested in your case notes, or your personal files.

Affects . . .

Ordinary citizens

Anyone seeking advice from an agency that gets some funding from MSD/OT

Helping agencies

NGOs that get some funding from MSD/OT for services to individuals

Budget services

Couple seeking advice on paying their mortgage now that one of them has been made redundant.

Family services

Parent seeking advice on dealing with a troublesome teenager.

Addiction services

Gambler seeking help to kick the addiction.

Why does MSD want this information?

The emphasis has changed from . . .

- Evidence on where to target government spending – ‘what works’

To . . .

- People who need help are matched to the right services and to know the ‘life journey’
- And later under media pressure.... 5 NGO’s involved is stressful ... monitoring number of agencies involved

Will personal information improve services?

The connection is not apparent.

Governments and service providers need information.

But we cannot ignore issues of . . .

- Privacy
- Purpose
- Risk
- Ethics

Why worry?

As a citizen who seeks help—

- You could potentially go on a database of “vulnerable people”
- Your children will be in the database
- You will be subject to risk profiling
- You don’t know how long the data will be held
- Or what it will be used/re-used for
- Or who will see it

Why worry?

As a service provider –

- Your service was built on the promise of confidentiality
- No agreement to provide data, no contract/funding
- People who need help may not seek it
- Funding cuts if service users refuse to go on database
- Hefty compliance costs
- No control of data use once handed over (consent for use)
- Professional ethics

Appendix One: Advantages and disadvantages to mandatory sharing versus opting out

	Mandatory	Sensitive services customers choosing to opt out
	Consent to share data is required to receive an MSD funded social service.	Customers opting out will still receive the MSD funded service. The phasing in of exempt services will start from July 2017, with all services included by December 2018.
Advantages	<p>Able to undertake complete cross analysis on social investment including collective impact across Government investment to better support customers and direct funding.</p> <p>Will better enable Government and Providers to track customer journeys where complex and longer term support is required.</p> <p>Support MSD to understand where and how to invest appropriately, based on effectiveness and efficiencies of services and/or Providers.</p> <p>Allows for a cohesive customer centred approach to services.</p> <p>Less ability to lobby customers and volumes.</p>	<p>Customers of sensitive services would have their data safeguarded to help protect their privacy and to facilitate their engagement with services.</p> <p>This mitigates the compulsory requirement to provide consent for sensitive services.</p>
Disadvantages	<p>Some customers are likely to have significant concerns, and/or refuse to provide information.</p> <p>There are concerns across the sector that the ability for a Government agency or Provider to decline service to a potential customer because they will not consent to sharing information potentially reflects the tensions between informed consent versus coercive consent.</p>	<p>MSD will not be able to assess the efficiency, effectiveness and ROI of services and programmes where customers choose to opt out or providing consent.</p> <p>Customers opting out may not receive the full benefit of seamless services if they are not able to be identified and appropriately supported by their Provider.</p>
Notes and caveats	<p>All customers and providers are required to share customer data on the appropriate MSD funded services, otherwise service is declined. Some services (eg medical and counsellors etc) require this as part of their professional accreditation.</p> <p>Some services such as low contact services will not and do not capture customer names etc.</p> <p>Note that some services already collect customer data, and some statutory services require consent and data sharing otherwise services cannot be provided.</p>	<p>CI needs to do further work to identify what services would be phased in and when, and what services will be exempt and provide anonymised data.</p>

Coercion

“The ability . . . to decline service to a potential customer because they will not consent to sharing information potentially reflects the tensions between informed consent and coercive consent.”

MSD report to Assoc Min Jo Goodhew March 2016

What social service providers said:

“The most hard to reach children and families will not reach out for help.”

“For me, privacy and confidentiality are the basis of the work I do with people in distress.”

“Whether family support, budgeting, counselling . . . the information is sensitive and private . . . Providing identifiable data to government agencies is risky. ”



Brenda Pilott

18 March at 09:23 · 🌐 ▼

On the subject of MSD collecting personal data on users of community social services, my message to minister Anne Tolley is a simple one:

- You won't get the answers you want about best use of Govt funds by collecting individual data.
- If it's not safe yet to collect data on sexual violence victims, it's not safe to collect it on other people needing help.
- You can't brush aside privacy and ethical concerns.
- It's wrong to link funding to data collection.
- This is not how you work in partnership with community organisations doing vital work.

Time to call a halt to this. It's the wrong thing to be doing.

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SUMMARY

Taking a stand worked:

High media exposure gets public debate going.

Privacy Commission inquiry, 500+ responses to online survey and input from ComVoices working group – report is damning of MSD approach. Minister responds that issues will be addressed.

Security breach occurs for those required to load data, Minister commissions independent review, report is critical of process.

PM acknowledges on Radio interview (8 May) that the “people whom the data is about should have control of that data”

The Data Landscape

(it's looking abit crowded!)

Data Futures Partnership

- Social Licence
- Data Commons
- Re-identification

What does good data use look like for NZ?

an alternative common's owned approach to creating data sharing platforms with high trust & control of participants

Stats NZ

IDI

Integrated Data Infrastructure

- wants to be Repository of all govt/NGO Data
- strict access criteria for researchers to anonymised data sets
- current capacity issues slowing expansion

IDIA

'Shared workspace' Shared Data system across agencies for service delivery

as opposed to a govt driven approach to sharing data about clients by agencies (altho some assurance of controlled access)

SIU

Social Investment Unit

- Data Exchange - tools to enable transfer of data between agencies, NGOs
- Analytics of IDI data
- Using Actuarial model for risk factors
- Some overview/oversight of what SI is in NZ & how applied by govt agencies

these may link - infrastructure

Superu

- Evaluation/Research function
- What is evidence telling us

Treasury

- Analytics of IDI data
- Inform budget plans
- Actuarial model to identify forward liability & risk factors (now sitting in SIU)

iMSD

- SI applied to welfare reforms

CI (MSD)

- Community Investment
- ICHD approach
- Funding 'what works' intent

NGO's

- Increasing use of CMS tools & using data analytic tools (eg PowerBI/ Tableau)
- More data-driven with intro of RBA, Intervention logics, Theory of change etc
- Investment needed to increase capability
- Some NGO's loading data into IDI

NGO's having to navigate across the whole landscape

Everyone wants 'our' data but who's data is it - our clients!

Big Data - multiple initiatives underway:

- Social Investment Unit – building a data exchange system for government (with a 5-year timeframe) (www.siu.govt.nz), - recent announcement to be new agency with Superu included
- Data Futures – leading discussion with citizens about data – “social licence” (www.datafutures.co.nz)
- Government endorsed principles of value, inclusion, trust and control proposed by the NZ Data Futures Forum (Feb 2015)

Big Data - more

- IDI – Integrated Data Infrastructure. Principal research database containing “de-identified” microdata about people and households (stats.govt.nz/idi-data)
- Data Commons – “A high-trust, lower-cost alternative to enable data integration and reuse” (datacommons.org.nz)
- And Superu, Treasury, DIA, and the NGO sector
- Interesting articles in Public Sector Journal Sept 2016 (ipan.org.nz)



What next: the Data/Evidence journey has just begun

- Minister Tolley and Adams announces change of approach

<https://www.beehive.govt.nz/release/next-steps-individual-client-level-data>

- Still fish hooks - intent to vary contracts by year end, risk of being a delay tactic to get past election
- Essential to stay informed, engaged and vigilante on the rights of privacy, trust and control
- Engage in social investment debate on what that actually means and looks like – actuarial approach is bad for outcomes! And what's the real purpose of ultra targeting?

<https://thespinoff.co.nz/politics/24-05-2017/is-social-investment-just-a-warm-and-fuzzy-cloak-for-seeking-to-shrink-the-state/>